BLADDER HEALTH

Muscle Invasive Bladder Cancer: A Patient Guide

Urology Care FOUNDATION™
The Official Foundation of the American Urological Association

Introduction

There will be over 80,000 new cases of bladder cancer in the U.S. this year. About 19,000 of them will be MIBC. However, Mike's personal story shows that there is life after a bladder cancer diagnosis. But you have to be alert, because bladder cancer often goes undiagnosed.

Many people shrug off what may look like minor symptoms of bladder cancer. Some may never know until they go for a regular checkup and find that they have bladder cancer. You must get to know the symptoms. If you see any of them, you must act quickly, just like Mike did.

One of the most important signs of bladder cancer is blood in the urine. Pay attention to your body. Tell your doctor if you see what looks like blood in your urine. There are ways to treat the disease and your medical team will be there to work with you towards recovery. Know that there is hope if you learn what to look for and see your doctor quickly. This guide will tell you about muscle invasive bladder cancer (MIBC) and what you can do about it

GET THE FACTS

What is bladder cancer?

The bladder is where the body stores urine before it leaves your body. Urine is the liquid waste made by your kidneys.

Sometimes our body cells do not divide in the orderly way that they should. This abnormal growth is cancer. Bladder cancer is cancer that begins in the bladder. A person with bladder cancer has one or more tumors (lumps) made up of abnormal and unhealthy cells. Muscle invasive bladder cancer (MIBC) is a cancer that spreads into the thick muscle deep in the bladder wall. It is a serious and more advanced stage of bladder cancer. MIBC is a more harmful kind of bladder cancer. It should be treated without delay.

What are the risks associated with bladder cancer?

- Smoking
- Workplace exposure to chemicals used to make plastics, paints, leather and rubber
- Cyclophosphamide, a cancer drug
- Radiation to the pelvis
- There may be a genetic link

How does bladder cancer develop and spread?

Most bladder cancers start in the inside lining of the bladder. MIBC starts in the inner bladder layers and then grows into the deep muscle. Over time the tumor may grow outside the bladder into tissues close by. The cancer may then spread to lymph nodes, the lungs, the liver and other parts of the body.

What are the symptoms of MIBC?

Blood in the urine (**hematuria**) is the most common symptom of MIBC. You may have it and have no pain. If you can see blood in your urine, do not ignore it. Tell your healthcare provider right away. Even if the blood goes away tell your doctor anyway.

Getting the right information is key to reducing the stress that comes with a cancer diagnosis.

***All words that appear in blue are explained in the glossary.**

GET DIAGNOSED

What tests are there for MIBC?

If your healthcare provider believes you may have MIBC, then he/she may send you to see a **urologist**. Your urologist will do a full history and physical exam. They also will do several exams and tests like the following:

- **Urinalysis** to test for blood and look for cancer cells
- **Comprehensive metabolic panel (CMP)** to see if your blood work is normal
- **X-rays, CT scan** or **MRI**
- **Retrograde Pyelogram** — an X-ray to look at your bladder, ureters and kidneys
- **Cystoscopy** — this very common procedure lets your doctor see inside your bladder. Your doctor will pass a tube (**cystoscope**) through your urethra into your bladder. The tube has a light at the end so that your doctor can see more clearly. There are two types of cystoscopy procedures:
    - o **Flexible cystoscopy** — the doctor uses a thin cystoscope that can bend. He/she will most likely use it in the office for **biopsy** or to look for an unusual lump. Usually, you will get a local anesthetic for an examination in the office.
    - o **Rigid cystoscopy** — the doctor uses a bigger, straight cystoscope that has space for instruments to pass through. This allows them to take samples or resect (cut away) the tumor. Usually, you will be put to sleep so that you will not feel what is happening
- **PET-scan** otherwise called a positron emission tomography
- **Transurethral resection of bladder tumor (TURBT)** may be done during cystoscopy as part of your diagnosis.

A **tumor grade** tells how aggressive the cancer cells are.

A **tumor stage** tells how much the cancer has spread.

How is MIBC measured and described?

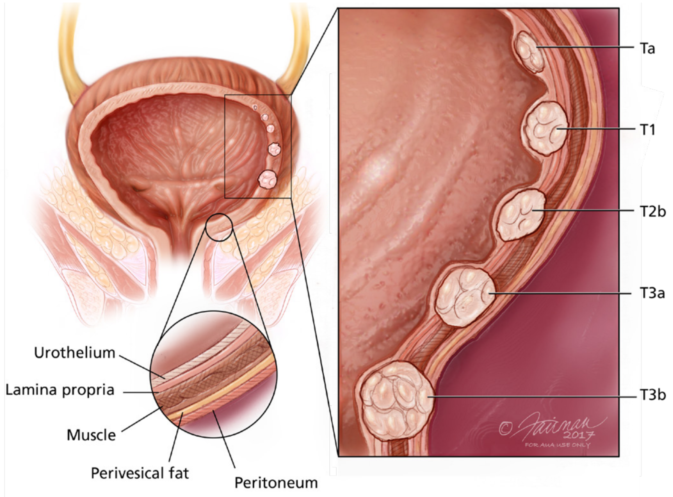
Grade and **stage** are two ways to measure and describe how cancer grows. Tumors can be low or high grade. High-grade tumor cells are very abnormal, and more serious. They are more likely to grow into the bladder muscle.

Doctors can tell the stage of bladder cancer by taking a small piece of the tumor. A pathologist in a lab will look closely at the sample under a microscope and decide the stage of the cancer. The stages of bladder cancer are:

- **Ta:** Tumor on the bladder lining that does not have invasion of any of the layers of the bladder
- **Tis:** Carcinoma in situ—A high-grade cancer. It looks like a reddish, velvety patch on the bladder lining
- **T1:** Tumor goes through the bladder lining but does not reach the muscle layer
- **T2:** Tumor grows into the muscle layer of the bladder
- **T3:** Tumor goes past the muscle layer into tissues surrounding the bladder
- **T4:** Tumor has spread to nearby structures. This can be the lymph nodes and prostate in men or lymph nodes and vagina in females.

In MIBC, the tumor grows into the deeper layers of the bladder wall (Stages T2 and beyond). The high-grade tumor cells of MIBC are more likely to spread and are harder to treat.

STAGES OF BLADDER CANCER



What are my options for MIBC treatment?

Your treatment options will depend on how much your cancer has grown. Your urologist will stage and grade your cancer and consider how to manage your care depending on your risk classification. Risk may be low, intermediate or high.

Treatment also depends on your general health and age, but there are basically two options for treating MIBC:

- Bladder removal **(cystectomy)** with or without **chemotherapy**. There is **radical cystectomy** and **partial cystectomy**.
- Chemotherapy with radiation.

> "Get a second and possibly a third opinion quickly. The one area you can control is selecting your healthcare partners – don't be afraid to ask the tough questions."
>
> *– Mike Lahm*

RADICAL CYSTECTOMY

A radical cystectomy is when your whole bladder is removed. Radical cystectomy is considered the best treatment for MIBC. The doctor will remove:

- The entire bladder
- Nearby lymph nodes
- Part of the urethra
- The prostate (in men)
- The uterus, ovaries, fallopian tubes, and part of the vagina (in women). Other nearby tissues may also be removed.

Most likely, chemotherapy will be given before removing your bladder for the best chance of survival. The treatment will probably be **Neoadjuvant cisplatin-based chemotherapy (NAC)**.

You will likely have your bladder surgery about 6-8 weeks after completing chemotherapy. If you do not have chemotherapy before surgery, then you may need it after surgery depending on the tumor stage. This is **adjuvant chemotherapy**.

If you have poor kidney function, hearing loss, heart problems and some other conditions, your doctor may not recommend chemotherapy.

PARTIAL CYSTECTOMY

For partial cystectomy, the doctor removes only part of your bladder. Partial cystectomy is less likely for MIBC patients because the cancer may be too advanced to consider this option. Your doctor may offer partial cystectomy in select cases of bladder cancer, when the tumor is in a specific part of the bladder and does not involve more than one spot in the bladder.

When your bladder is removed or partly removed, you will have another way to store urine and remove it from your body. This is called **urinary diversion**. There are several methods of urinary diversion such as **urostomy**, **ileal conduit**, **continent cutaneous reservoir** and **orthoptic neobladder**. Descriptions of these methods are at the end of this guide.

CHEMOTHERAPY WITH RADIATION

Radiation alone is not given for MIBC. It is usually done along with chemotherapy and after surgery. Chemotherapy with radiation may be used for **bladder preservation** (keeping the bladder or parts of it). Your doctor may suggest bladder preservation when radical cystectomy is not an option or is not wanted.

Before starting chemotherapy and radiation, your surgeon will resect (cut away) the tumor during a **trans urethral resection of bladder tumor (TURBT)**. He/she will also remove your lymph nodes. This is done to try to get all of the cancer cells possible.

Some drugs that may be used along with radiation are Cisplatin, 5-FU and Mitomycin-C. If you get this treatment you must follow-up with your doctor. You will need to have ongoing cystoscopy exams, imaging tests (e.g. CT scan), and other procedures to monitor the tumor.

Radiation therapy uses high-energy rays to kill cancer cells. The radiation comes from a large machine. The machine aims beams of radiation at the bladder area in the abdomen. You may go to a hospital or clinic five days a week for several weeks to get radiation therapy.

> "I learned that the recovery process is seldom a straight line, so patience and perseverance are required."
>
> *– Mike Lahm*

What are the Side-Effects after MIBC treatments?

You will have side effects after most MIBC treatments. But, there are things you can do to help feel better. If you smoke, get help to stop. Start exercising and eating more fruits and vegetables. Healthy eating will help you recover faster.

Here is some of what you may expect:

- Pain — work with your healthcare team to get control of your pain. There are many ways to do this.
- Bowels — Your bowel function may return more slowly after your surgery.
- Radiation — this therapy is painless but it does have side effects including nausea, vomiting and diarrhea.
- Leaks — from the stoma (opening).
- Infections—from your urinary diversion. Kidney infections are possible too.
- Deep vein thrombosis (DVT) — blood clots that form in veins in your legs.
- Hot flashes — for women who have not had menopause and had their ovaries removed.
- Sex and fertility issues — treatment for bladder cancer can affect your sex life. If you are a woman and your doctor removed part of your vagina, it may make sex difficult. You may also not be able to have children if your uterus was removed as well. If you have a partner, you may be worried about your relationship. Your doctor may recommend that you talk with someone who specializes in sexual issues after cancer treatment.

AFTER TREATMENT

Is there anything I must do after treatment?

Be sure to follow-up with your healthcare provider, as they will need to assess you for some time after treatment. You should expect to see your doctor for several assessment and evaluation visits. These will include some or all of the following:

- Imaging (e.g. CT scan) about every 6-12 months for 2-3 years; and then annually.
- Laboratory tests every 3-6 months for 2-3 years; and then once per year after. Kidney and liver function tests will be a part of these tests.
- Assessment for quality of life issues such as urinary symptoms and sexual function.

Remember, get regular exercise, eat a healthy diet and do not smoke! Your healthcare provider may also recommend a cancer support group or individual counseling.

> "You play a key role in your recovery. Do what they teach you in the hospital and, even if you must force yourself, walk every day. Be vigilant in your follow-up."
>
> *– Mike Lahm*

What are my chances of recovery after MIBC diagnosis?

If you have a cystectomy (surgical removal or partial removal of the bladder) the cancer return rate can be from 20-30% for stage T2. It can be 40% for T3, greater than 50% for T4 and usually higher when lymph nodes are involved. If your bladder cancer does recur, it most often will happen within the first two years after bladder surgery.

Regular follow-up is very important.
Make sure you stay in touch with your care team!

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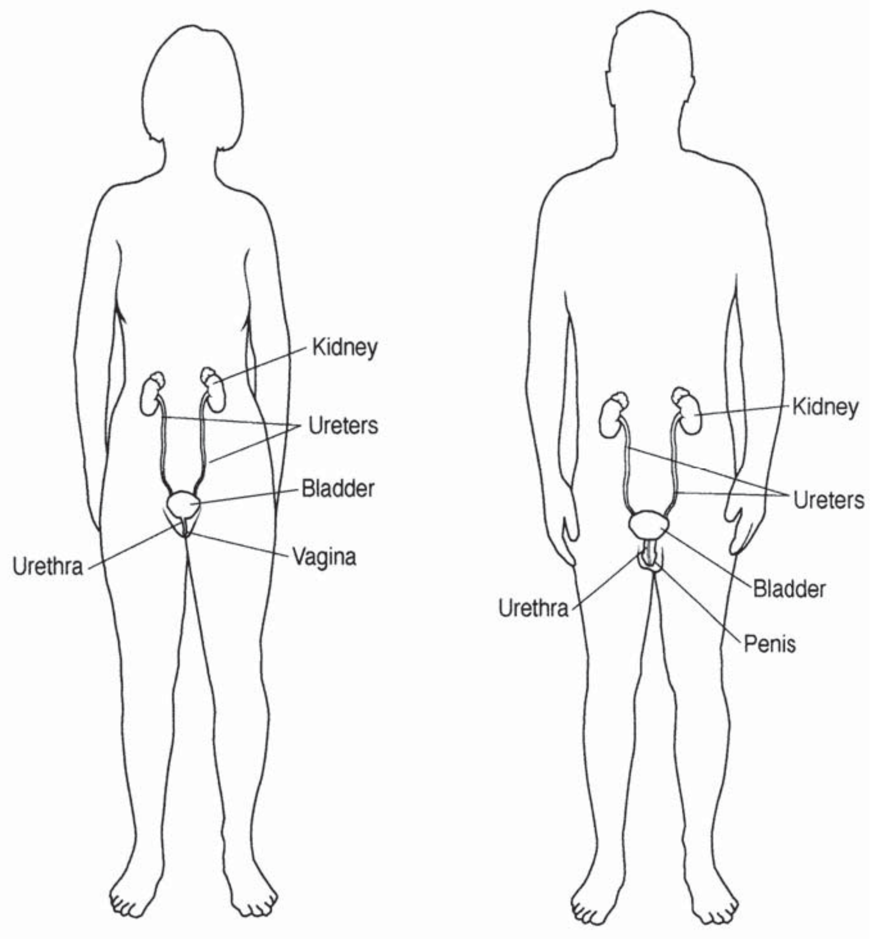
Radical Cystectomy with Ileal Conduit Urinary Diversion

Here is important information about your treatment for bladder cancer. Your doctor has recommended surgery to remove your bladder. This handout gives you information about your surgery, hospital stay and recovery.



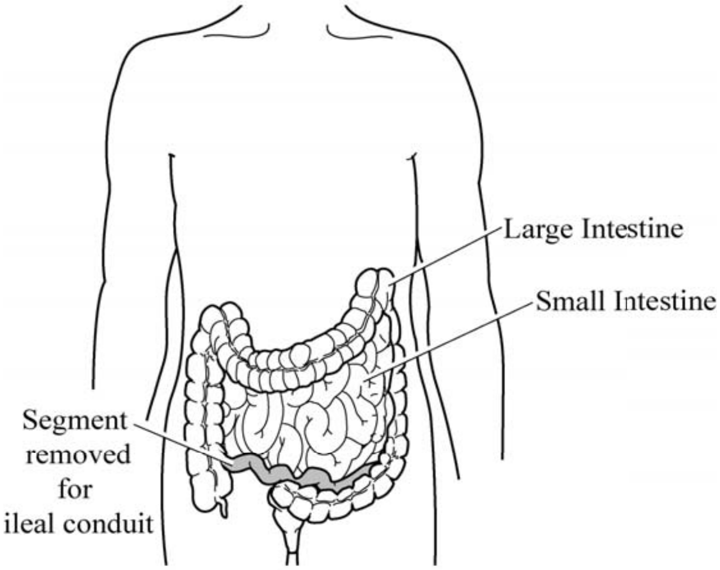
What does my urinary system look like?

The urinary system has two kidneys, two ureters, one bladder and one urethra. The kidneys are bean shaped organs that filter your blood and removes water and waste through the urine.

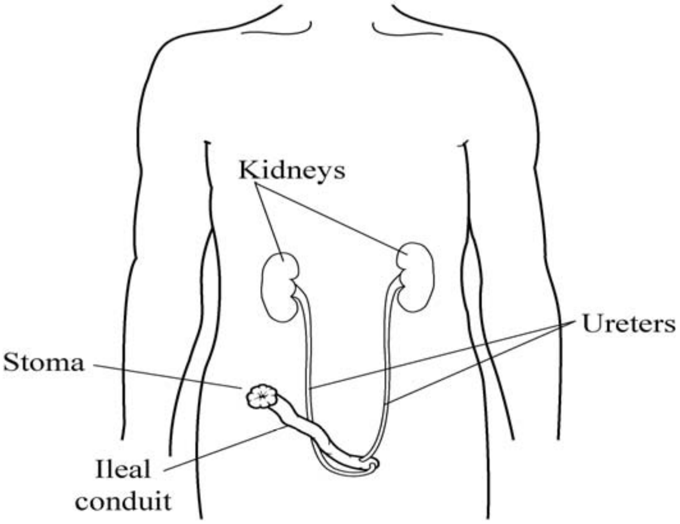
Connected to each kidney are narrow tubes called ureters. Ureters carry urine to the bladder. The bladder stores urine until you are ready to urinate. Urine leaves the bladder through a narrow tube called the urethra. The female urethra is just above the vagina. The male urethra passes through the prostate gland and penis.

Radical Cystectomy with Ileal Conduit Urinary Diversion

A cystectomy is surgery to remove the bladder. **In men**, the bladder, prostate, seminal vesicles and lymph nodes are removed. **In women**, the bladder and lymph nodes are removed. The ovaries, fallopian tubes, uterus, cervix, vagina and urethra may also be removed. Your doctor will talk with you about the surgery and what is best for you.



An ileal conduit, also called a urostomy, is a way to redirect urine to drain through a small opening in the abdomen called a **"stoma"** During surgery, a short piece of the small intestine (ileum) is connected to the ureters. One end of the conduit will be closed and the other end will be pulled through the skin of your abdomen to make the new stoma.



After surgery, the stoma will be swollen and may take several months to shrink to a permanent size. The stoma should always be soft, moist and pink to red in color. The stoma does not have nerve endings, so it should not be painful to touch. It is normal to see a small amount of mucus around the stoma.